

Primary Care Providers

Frequently asked Questions

PARENT's CONCERN	INFORMATION
Cost of the testing	<p>Most insurers, including Medicaid, cover the cost of newborn screening testing as part of the obstetric diagnostic related group (OB DRG).</p> <p>The laboratory charges the hospital \$38.50 for the newborn screen. The hospital charge for collection and handling of the specimen vary, and are not regulated by the State Newborn Screening Program.</p>
The heelstick	<p>The heelstick procedure requires a small puncture to the baby's heel to collect five drops of blood. Hospital staff are trained to follow procedures to minimize the risk of infection. The poke to the baby's heel usually heals quickly and studies show little pain is felt during this time. Parent may nurse during this time to sooth the baby.</p>
The testing in general	<p>Most people are assured when they understand that this kind of testing:</p> <ul style="list-style-type: none"> • is routinely done • has been done for over 40 years, • is required in all U.S. States, industrialized countries, and some developing countries, and • has saved thousands of newborns from developmental disabilities, long-term physical problems, and infant death.
Child's insurability if found to have a condition	<p>The Genetic Information Non-Discrimination Act is an important piece of Federal legislation that was passed by Congress and signed by the President in 2008. This Act provides some protections from using genetic information to discriminate against individuals. While this is a legitimate concern, two circumstances that should be considered:</p> <ol style="list-style-type: none"> 1) The child is found to have the condition on screening and preventive treatment ensures a healthy life, or; 2) The child is found to have the condition only after damage has occurred (because they did not receive the screening results) resulting in developmental disabilities, physical disability, or death. <p>The child with the diagnosis could have problems getting insurance, whether screened or not. It's preferable to get the diagnosis in time to prevent the damaging effects of the condition.</p>

Ability to care for a child with a metabolic condition	There’s no question, families face many challenges with some of the conditions. But there are many good resources available in Nebraska, so families don’t have to "go it alone.”												
Availability of treatment for one of the disorders	There are also specialist who are able to work closely with families to help them provide the care their child needs. Clinics have allied health professionals with the expertise in metabolic conditions, endocrine, hematologic conditions, and CF Care. Genetic counseling services are also available to help answer additional questions.												
Refuse to have the testing done	The law in Nebraska does not allow parents to sign a "waiver" or "dissent" from the required newborn screening panel. It’s not allowed for any reason, religious or otherwise. County courts in Nebraska have heard three cases, and in all three the judge ruled the child must be screened. An appeal to the Nebraska Supreme Court was heard in 2005. The Nebraska Supreme Court unanimously upheld the requirement that all newborns must be screened. Likewise, a Federal District Court Ruling in 2006 upheld the law.												
Social stigma associated with having an inherited condition	An inherited condition can have major implications for the child’s quality of life. However, the quality of life can be improved with early intervention and treatment. Parent to parent support groups and networks are available to help families deal with this.												
Unsure if they understand	<p>The conditions screened are many and complex. Physicians should provide a basic explanation of newborn screening to parents, and offer to discuss any questions the parents have. This is especially important when literacy skills may be limited.</p> <p>Language barriers may also be an issue. Oral interpreters may be needed if literacy levels are in question, or if the parents don’t speak or read any of the available languages of the educational materials. The "Parent’s Guide" is available in the following languages:</p> <table><tr><td><i>English</i></td><td><i>Spanish</i></td><td><i>Vietnamese</i></td></tr><tr><td><i>Russian</i></td><td><i>Chinese</i></td><td><i>French</i></td></tr><tr><td><i>Karen</i></td><td><i>Sudanese</i></td><td><i>Anuak</i></td></tr><tr><td><i>Dinka</i></td><td><i>Nuer</i></td><td></td></tr></table>	<i>English</i>	<i>Spanish</i>	<i>Vietnamese</i>	<i>Russian</i>	<i>Chinese</i>	<i>French</i>	<i>Karen</i>	<i>Sudanese</i>	<i>Anuak</i>	<i>Dinka</i>	<i>Nuer</i>	
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